

## Rain or Shine, They Go to their Support Group!

ASCC clients Larry Wilson and Jake Bennett have been longstanding advocates of the SCI support groups for the past 15 years. Everett "Red" Goff joined these two gentlemen five years into the game, making him a ten-year advocate for SCI support groups.

Throughout the years, these men have seen many people come and go. Rain or shine, the three of them, without fail, meet once a month (sometimes twice a month) to talk/listen, laugh/cry, comfort/be



Jake Bennett (left), Everett "Red" Goff (middle) and Larry Wilson (right) support their Support Group!

comforted and educate/learn through their SCI support group.

"Many people who have a spinal cord disability feel they are alone and that no one understands what they are going through," says Larry Wilson. "The support group helps you realize you are not alone and that you share a common goal: to share different opinions and strategies on how to cope with your disability."

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## ASCC Receives Client Report Card

In order to monitor and improve its services, ASCC asked a random group of clients to grade the agency on its delivery of equipment and services. This September an anonymous survey was mailed to 25 percent of ASCC's clients; 150 clients returned the questionnaire for a response rate of 28.1 percent. Highlights of the survey findings follow.

The respondents were very similar to all clients eligible to receive a survey. Sixty-five percent were male and ages ranged from under 9 to over 60 years. Fifty-nine percent

of the respondents' disability was due to an injury, 29 percent to spina bifida, 8 percent to "other" causes and 4 percent to a disease process.

When asked to rank what ASCC services were most important, respondents listed: purchased services (25.1%), case management (22.5%), long-term attendant care (14.0%) and the *Spinal Courier* newsletter (14.0%) as the top four services. Seventy-four percent of all respondents reported that they read all or most of the newsletter. The two services that respondents

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## May 21, 2004 — Mark Your Calendar!

The ASCC statewide conference will be held Friday, May 21, 2004, at the C.A. Vines Arkansas 4-H Conference Center in Ferndale, AR. Mark your calendar! Registration forms will be mailed in the spring with details as the program and speakers are finalized.

## SPINAL COURIER

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## With Thanks

*Donations this quarter from:*

**Jimmy Ashley**  
**Anonymous Donor**

*In Memory of Stan Parker:*  
**Linda & Lindell Hitchcock**  
**Jim Todd**

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517**(voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission**  
**1501 N. University, Suite 470**  
**Little Rock, AR 72207**

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### Post-Polio Health International

Dear Editor:

I recently received this notice and wanted to pass it on to the *Spinal Courier* readers:

Gazette International Networking Institute (GIN) has changed its name to Post-Polio Health International and has developed a new membership structure. The new name clearly focuses on living with the late effects of polio and reaffirms an ongoing interest in international issues. It is meant to project the broadest meaning of "health,"

encompassing the physical, emotional, social, psychological and spiritual aspects of individuals' lives. The new membership structure is designed to strengthen Post-Polio Health International's ability to advocate for its constituents.

They can be contacted on the web at [www.post-polio.org](http://www.post-polio.org) or by calling **314-534-0475**.

*Robert Griffin*  
*ASCC Case Manager*  
*Russellville, AR*

### From the Director

Happy New Year! As I write this, it isn't 2004 yet, but I'm already looking forward to it. New beginnings are always fun! The New Year brings the start of new projects, new opportunities and a chance to "start over." One of the things that will "start over" is our registry count. As you may know, the Arkansas Spinal Cord Commission (ASCC) maintains the oldest and most comprehensive spinal cord disability registry in the Country!

We have records on everyone who has been reported with a spinal cord disability since 1977, when the law that established the registry went into effect. That includes 5,256 cases as of December 1, 2003. Of those, a little less than half, or 2,230, are presently active—folks presently living in Arkansas with a spinal cord disability. Members of this exclusive club, that no one chose to join, live in every county in Arkansas. Their ages range from 6 months old to 92. About half of these folks had an injury (mostly car crashes, followed by falls and gunshot wounds). About a fourth were born with spina bifida. The rest made the club by getting some disease process, like multiple sclerosis, spinal stenosis or tumors. A few have rare diseases like Friedreich's Ataxia, Guillain-Barré Syndrome and other things I can't pronounce!

While ASCC isn't looking for new members to the club, we know that about 175 will be reported each year, adding to our registry and accessing our services. That 1977 law requires that doctors, nurses, social workers and others who come in contact with new cases report them to the Commission within five days of identification.

If you know of someone who hasn't been reported, please call us! We can't help anyone we don't know about!

*Cheryl L. Vines*

# New Law Regarding Accessible Parking in Effect

On July 16, 2003, Act 1353 of 2003 went into effect, which states only those vehicles that are loading or unloading wheelchairs will be authorized to park in the spaces designated as "van accessible." This includes cars, vans or pickup trucks as long as someone in that vehicle is getting in or out with a wheelchair or other mobility device.

The other accessible parking spaces may be used by anyone who has an authorized plate or placard as long

as they are in that vehicle. Violators will be subject to a fine of \$100-\$500 for the first offense and \$250-\$1,000 for subsequent offenses. In addition, the vehicle may be towed at the owner's expense.

For more information concerning this new law, interested persons may call Barry Vuletich, Executive Director of the Arkansas Governor's Commission on People with Disabilities, at **501-296-1626**.

## ASCC Report Card

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indicated that ASCC should provide were financial assistance and transportation.



Almost all respondents reported having a telephone (92.7%) and television (98.0%) and most have a VCR (85.3%). Sixty-one percent reported owning a computer with about fifty percent having internet access (50.7%) and an e-mail address (48.3%). However, of the respondents who have internet access and thus the capability to visit ASCC's website, only 27.6% have actually visited the site.

Forty-five percent of the respondents indicated that ASCC had purchased equipment, medication or another item for them in the last year. The top five items purchased were wheelchairs, cushions, ramps, home modifications and medical supplies. Of the respondents who received an item, 91.5 percent reported that the quality of the item purchased was excellent or good. Seventy-eight percent indicated that the item was delivered in a timely manner.

A few respondents indicated that they were waiting for their Case Manager to call or that they didn't know who their Case Manager was. **If you have a pressing need, contact your Case Manager!** To find out who your Case Manager is call **1-800-459-1517** or go to [www.arkansas.gov/ascc](http://www.arkansas.gov/ascc) and go to the "Contact ASCC" link.

Twenty-five percent of respondents reported that they saw or spoke with their Case Manager in the last month. Seventy-three percent said that their Case Manager was always or often helpful and that 93.9 percent of respondents' telephone calls were answered within three days.

Seventy-six percent indicated that their Case Manager was always or

*If you have a pressing need, contact your Case Manager!*

often timely in meeting agreed upon client needs. Overall, 57.6 percent of respondents gave their Case Manager an "A" in knowledge and 28.0 percent graded them a "B."

## Higher Education Scholarships

**January 30, 2004**, is the deadline for applications for the Arkansas Governor's Commission on Disabilities scholarships. Contact Barry Vuletich by e-mail at [bmvuletich@ars.state.ar.us](mailto:bmvuletich@ars.state.ar.us) or call him at **501-296-1626** for more information and to request an application.

Completed applications for the Spina Bifida Association of America's four-year education scholarship fund must be postmarked **no later than February 15, 2004**. You can download copies of the application and criteria guidelines from their website, [www.sbaa.org](http://www.sbaa.org) or call **800-621-3141**.

At the state level, the Spina Bifida Association of Arkansas scholarship applications are **due by August 15, 2004**. Contact Vicki Rucker by e-mail at [sigmondv@sbcglobal.net](mailto:sigmondv@sbcglobal.net) or call her at **501-978-7222** for details and applications.

Please remember, all scholarships require various documents to accompany them. It is advisable to start early to make sure you have all the letters of recommendation and other documents necessary to turn in your completed applications.

When asked how satisfied they were overall with ASCC services 61.2 percent of respondents indicated they were very satisfied and 22.9 percent said they were somewhat satisfied.

The survey findings have been presented to the ASCC Commission and staff. The findings have been taken into consideration in setting agency goals and objectives for the 2004 year.



# Common Medications Used in SCI Medicine

## Part I - Spasticity

By Tom Kiser, M.D., ASCC Medical Director

When the spinal cord is damaged the resulting medical problems vary, depending on the location and amount of irreversible damage to the spinal cord. Your need for medicines will vary from another individual's need, because no two spinal cord injuries are exactly the same, and no two individuals are exactly the same.

However, there are certain medications that I use in my practice more than others. So, in the next couple of issues of the *Spinal Courier* I will discuss the most commonly used medications, give you my perspective on how they can best be used, and alert you to possible pitfalls.

Spasticity medication is used to decrease the negative aspects of spasticity such as poor motor control, discomfort, muscle jerks, and functional problems with transfers and wheelchair seating. However, we do not want to eliminate the positive aspects of spasticity such as decreased muscle atrophy, tone to enable standing and lower extremity movement, and even bladder spasms to enhance bladder emptying.

The most common medications used for spasticity are: baclofen (Lioresal), tizanidine (Zanaflex), and diazepam (Valium). Some other medications which can be tried are gabapentin (Neurontin) and dantrolene (Dantrium).

### Diazepam

I have not found the need to use diazepam in my new patients with SCI. Diazepam has addictive potential and secondary issues; however, I continue to prescribe it for individuals who have been on it

for a long time because it is very difficult to get off of it due to withdrawal problems. To get off of diazepam requires a slow taper and extreme effort on the part of the patient. Other medication can be used to minimize the side effects of withdrawal.

### Baclofen

Baclofen (Lioresal) has been used for years to treat spasticity and is my first line choice in managing spasticity. It is safe and there have been no reports of liver toxicity even at very high dosages. The only problem with baclofen is that

*Living with spasticity successfully is now possible no matter how bad the spasticity is for you.*

you cannot stop it suddenly, or you may have severe withdrawal symptoms (hallucinations, agitation, and even seizures).

So, if your medicine is running low or you know you have to have surgery and you will not be able to take anything by mouth for a couple of days, I recommend tapering down to a low dose before stopping it entirely. The normal daily dosage is 10 to 80+ mg (divided doses). The effect of oral baclofen lasts about six hours, so it is prescribed either three or four times a day.

The maximum dosage listed in the *Physicians Desk Reference* (PDR) is 80 mg, but some spinal cord physicians will push the dose higher (120 to 240 mg a day) to control spasticity or until the side effects of lethargy and drowsiness prevent higher dosages. I will often



Tom Kiser, M.D., ASCC Medical Director

add a second medication such as tizanidine (Zanaflex) before going to very high doses because it acts by a different mechanism and often gives a beneficial boost to spasticity control.

### Tizanidine

Tizanidine (Zanaflex), as mentioned above, can be used with baclofen but it is also very beneficial by itself. Its main side effect is drowsiness, but it can also cause dry mouth, low blood pressure and (very rarely) visual hallucinations. I often start it as a bedtime dose because it helps with sleep. I then very slowly start a low dose of tizanidine during the daytime hours. The side effect of drowsiness will slowly wear off.

Tizanidine can raise liver enzymes, so periodically checking laboratory values is necessary. It does not have the same problem of withdrawal that baclofen has and that may be important in some individuals who may have problems taking their medication as scheduled.

### Gabapentin

Gabapentin (Neurontin) is a good medication to help decrease the burning, deep, hard to describe neuropathic pain associated with SCI. However, it also has an antispasticity effect and in patients with both pain and spasticity it is

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## Spasticity Medication

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a good choice. The normal dosage is 100 to 3600 mg in divided doses. It is a seizure medication and has the main side effect of drowsiness, but the drowsiness is usually less than that associated with baclofen or tizanidine. Gabapentin is cleared by the kidneys and does not cross react with a lot of other medication.

### Dantrolene

Dantrolene (Dantrium) is the last medication I want to talk about. It inhibits the release of calcium needed for the muscles to move and thus decreases spasticity at the muscle level. It can make you drowsy but this side effect is minimal. The normal dosage is 25 to 400 mg a day divided into three to four doses a day. The main drawback is liver toxicity, and laboratory tests must be followed to assess for any liver problems, which are reversible if caught early.

If all oral medication fails to control your spasticity, we now have the Intrathecal Baclofen pump, which has been very beneficial to a lot of my patients. So living with spasticity successfully is now possible no matter how bad the spasticity is for you.

In the next issue of the newsletter I will discuss medications to help control your bladder.

## Dandridge and Carr Receive Abilities Awards

The inaugural Arkansas Abilities Awards were presented at a luncheon on October 16, 2003, at the Robinson Center in Little Rock. The luncheon was hosted by Arkansas Rehabilitation Services and the Governor's Commission on People With Disabilities, and sponsored by Wal-Mart and Snell Prosthetic and Orthotic Laboratory.

The awards were designed

to recognize Arkansans with disabilities who are pursuing employment and employers who hire individuals with disabilities. Governor Mike Huckabee, who presented the awards, noted in his comments that people's abilities are what count!

Two of the six Abilities Award recipients were ASCC clients. Tim Carr of Little Rock sustained his spinal cord injury in a motorcycle crash in 1978. His own injury-related litigation provided him with an interest in studying laws.

Since that time Tim has pursued his education and, despite many obstacles, received his JD (Juris Doctor) from the UALR Law School. He is presently an attorney, specializing in personal injury cases. Over the years, Tim has served as a mentor and role model for many young people with spinal cord disabilities.

Bobby Dandridge of Pine Bluff has lived with his spinal cord disability since a car crash in 1990 left him with paraplegia. Bobby was commuting to school in Little Rock when he sustained his injury. Though he, too, met numerous obstacles along the way, he kept his eye on his goal and in 2001 received his associate's degree in

computer networking from South Arkansas College.

Today Bobby is the Web Coordinator at University of Arkansas Pine Bluff, and is also working towards his bachelor's degree in computer science there. Despite his busy schedule, Bobby finds time to serve as a speaker in ASCC *Split Second Decision* spinal cord injury prevention programs.

"Tim and Bobby represent many Arkansans with spinal cord disabilities who are out there accomplishing their goals and returning to the workforce," said ASCC Executive Director Cheryl Vines, who attended the luncheon. "We are pleased to see them recognized for their ABILITIES!"

ASCC Commission members and staff congratulate Tim Carr and Bobby Dandridge on being two of the first Arkansas Abilities Awards recipients.



## West Memphis Miniconference a Great Success!

West Memphis ASCC Case Manager Sharon McCoy (*left*) presents an Arkansas Razorback tee shirt as a door prize to Jan and Roger Williams of West Memphis (*right*).

The Williams were among nearly 50 clients, family members and

health care providers from eastern Arkansas and west Tennessee who attended the ASCC *Living Well With Spinal Cord Injury* miniconference held at MidSouth Community College on October 30, 2003.

# Up Close and Personal: Robert Griffin

*This is the first in a series of articles profiling the ASCC Case Managers.*



Thirty years as a Rehabilitation Counselor is a long time to be committed to one career. However, this is actually Robert Griffin's second career path—the first being 12 years of active duty in the U. S. Air Force. "Commitment and dedication are the words that come to mind when describing Robert," says Client Services Administrator Patti Rogers.

Robert's desire to help others was a great motivator in obtaining a Master of Rehabilitation Counseling from Arkansas State University. Since then he has shared his knowledge and expertise with many other professionals and the individuals with spinal cord disabilities he serves in north central Arkansas. His knowledge of community resources, support groups and reference material has proven invaluable to the Spinal Cord Commission and to those individuals on his caseload.

In March of this year Robert, along with fellow ASCC Case Manager Kay Lynn, had the honor of receiving a Spirit Award presented by Arkansas Independent Living Council Chairperson Sydney Case. The Spirit Award is given to those individuals who have shown spirit and caring far beyond the scope of their job responsibilities. Robert demonstrates this daily in his commitment to serving individuals with spinal cord disabilities.

## **PROFILE:**

**Date And Place Of Birth:** June 23, 1939, in Syracuse, N.Y.

**The Animal I Most Identify With Is:** A lap dog, moves slowly but usually knows where he's going...to the food dish

**I Absolutely Will Not Eat:** Anything that is bigger than I am and anchovies

**My Last Meal Would Be:** Fried chicken and the fixins'

**If I Did Not Live In Dardanelle, I Would Want To Be:** In Russellville, just across the river to still be close to the wife Peggy, children and grands

**My Favorite Movie Is:** The 1940's Walt Disney movie, *Song of the South*

**My Favorite TV Show Is:** *Nightly News* & weather

**My Favorite Song Is:** *Amazing Grace*

**The Guests At My Fantasy Dinner Party Would Be:** All the lovely people I have ever met over the years working at ASCC

**I Am Most Comfortable With People Who Have:** Time to listen and enjoy the simple things in life

**My Favorite Pastime Is:** Fishing when convenient (or inconvenient, according to my wife)

**My Pet Peeve Is:** Trying to keep up with this impossible job

**The Best Advice I Ever Received Was:** If you are going to do a job, try to do it right the first time

**My Favorite Saying Is:** Folks won't care how much you know until they know how much you care

**I Knew I Was Grown Up When:** When I got to fly in those BIG USAF airplanes

**The Latest Book I've Read Is:** *Calvin and Hobbes 10th Anniversary Book* (of cartoons)

**The One Thing I Always Wanted To Do But Have Never Had The Chance Was:** Take a leisurely tour of the British Isles—they speak almost the same language over there

**My New Hobby Is:** Collecting Arkansas souvenir plates (still looking for a BEAR state one)

**One Word To Sum Me Up:** Encourager

# Rain or Shine

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The idea of going to a support group the first time can be intimidating. "I went to my first support group because I couldn't find anything else to do that day," relates Jake Bennett. "I felt so good afterwards, and I just kept coming back." Some people think joining a support group means you're not in control of your life—that you need others to help you solve your problems. When in fact, a support group is there for exactly what it says—support—people encouraging and supporting each other through sharing and listening. It is a safe forum for discussion to help people on their path to recovery, to provide insight and guidance to manage day-to-day life in a healthy way.

These support groups are specifically designed for people who have experienced spinal cord disabilities. We do not prescribe or diagnose in our support groups—we suggest and listen. The support groups are meetings where people can get information about spinal cord disabilities, different types of therapy, workshops and learn of professionals who specialize in different areas of spinal cord disabilities. More importantly, they are safe and confidential discussion groups where people can share their stories and experiences.

People only benefit from a support group meeting when they use what the support group has to offer. "I learn something new each time I attend one of the support groups," asserts Red Goff. Within the support group environment, you will discover that everyone is at a different level in his or her recovery. Also, many have enlightening stories to tell about their journey and the challenges and successes along the way. It's encouraging to have people return each month and share how well they are managing their disability, how insightful was a suggested book or how helpful was

one of the recommended professional support services.

**The White County SCI Support Group** meets on the first Tuesday of every month, on the first floor of the White County Hospital Rehabilitation Building in Searcy. This group is a "discussion" group for clients, where you share experiences and relate personally one-on-one to others with spinal cord disabilities. This is also a "closed" group, meaning family members are asked not to attend, due to the confidential issues discussed among the clients. Call Larry Wilson at **501-724-3504** to confirm dates.

**The St. Vincent SCI Support Group** meets on the third Thursday every month, on the ground floor of St. Vincent's Hospital in Sherwood. This group is an "informative" group open to both clients and family, where speakers are invited to provide education and guidance for people with spinal cord disabilities. Open discussion is encouraged after the presentation. Lunch is also provided, so for an estimated head count for plates, we ask that you contact Judith in ASCC's Little



Rock office at **501-683-1124** to let her know you'll be attending.

**The Baptist Health Rehabilitation Institute SCI Support**

**Group** meets quarterly (i.e., **February, May, August, November**) on the **first Friday of the month** (full week) at **11:30 a.m.** in the Education Room located on the ground floor of BHRI in west Little Rock. This group is an "informative" group open to anyone interested in spinal cord disability. The meetings have featured speakers followed by open discussion. Please contact Judith at **501-683-1124** for more information about this group and to add your name to the lunch list.

**So mark your calendars now** as a reminder to give one of these groups a try!

"I've gained so much through my experiences with the SCI support groups," claims Larry Wilson. "I can't imagine anyone leaving one of these groups without a stronger sense of themselves as a person, and a better understanding of their disability."

## 2004 Monthly SCI Support Groups Dates and Times:

### White County SCI Support Group

**10:30am-12:00pm**

January 6, 2004  
February 3, 2004  
March 2, 2004  
April 6, 2004  
May 4, 2004  
June 1, 2004  
July 6, 2004  
August 3, 2004  
September 7, 2004  
October 5, 2004  
November 2, 2004  
December 7, 2004

### St. Vincent SCI Support Group

**11:30am-1:00pm**

January 15, 2004  
February 19, 2004  
March 18, 2004  
April 15, 2004  
May 20, 2004  
June 17, 2004  
July 15, 2004  
August 19, 2004  
September 16, 2004  
October 21, 2004  
November 18, 2004  
December 16, 2004

*Please call ahead to confirm.*



# Spina Bifida Association Christmas Party for Children and Families

The Spina Bifida Association of Arkansas hosted a Christmas party for children with spina bifida and their families on December 7, 2003, from 2:00 to 4:00 p.m. at the Brandon Center of Arkansas Children's Hospital. Forty-six children and their families from all over the state attended the party. Total attendance was over 150 persons, including representatives of the Corvette Club and four motorcycle clubs.

Everyone enjoyed the refreshments and a puppet show. All of the children were given rides in the corvettes and in motorcycle sidecars—great fun!!!



*Matthew Bell of Benton, AR is given a goody bag by Santa and his helpers at the Christmas party hosted by Spina Bifida Association of Arkansas on December 7, 2003.*

Needless to say, every child in attendance received a goody bag and present from Santa.

## McCluer Education & Resource Center News

We have a great VHS video in the McCluer Education and Resource Center. ***Wheelercise*** is designed for individuals who rely on wheelchairs as their main mode of transportation. The exercises can be safely and conveniently done in a seated position. Two separate exercise routines are on one tape: beginners for those just starting out or for senior citizens, and advanced for younger or more athletic persons. Call Judith at **296-1792** or **1-800-459-1517** to check out this very useful video.

Need resources closer to you? Check with your local ASCC Case Manager! All regional Case Managers have resources available for you to check out at their offices. From medical information to personal care—they probably have just what you need!

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